7-1-1987

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A Thesis
Submitted to the Faculty of
Mississippi University for Women
in Partial Fulfillment of the Requirements
for the Degree of Master of Science in Nursing
in the Division of Nursing
Mississippi University for Women

Summer, 1987

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Acknowledgements

This researcher would like to express her appreciation to the members of the M.U.W. graduate nursing faculty, with special thanks to Mrs. Mary Pat Curtis, Dr. Rayma Skinner, and Dr. Phyllis Werner for convincing me that I could do it.

Loving gratitude is expressed to my wonderful parents, mother-in-law, and sister-in-law for believing in me, and for lovingly caring for my children so that I could do it.

Last, but not least, my love and appreciation to my children, Chad, Jennifer, and Melissa, and to my husband, James, for loving and supporting me through it all. I could not have made it without you.

In Loving Memory of Michael

Abstract

This study was descriptive in nature, designed to identify differences in coping strategies of spouses of Alzheimer patients who are cared for at home. Data were collected using the Chronicity Impact and Coping Instrument: Spouse Questionnaire.

The sample consisted of 14 subjects (3 males and 11 females) who met the criteria for the study. Subjects ranged in age from 60 to 86 years with an average age of 68.9 years. One Black and 13 Caucasians participated.

To test the hypothesis, data were analyzed using percentiles. Eight coping strategies were found to be used "More often" by the participants. Males chose "Ignore/try to forget," "Hide feelings," "Smoke," and "Yell/scream/slam doors," and "Ask for help" more often than females. The females chose "Cry," "Busy self with other things," and "Exercise" more often than males. The males chose to "Get away" and "Ask for help" less often than the females. None of the participants chose "Get away more" as a coping strategy. Females chose a variety of coping strategies. Since differences in coping strategies were identified, the researcher rejected the null hypothesis.

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Chapter I

Research Problem

Interest in the study of Alzheimer's Disease began in 1907 with a description by Alois Alzheimer of a middle-aged patient with personality changes, progressive deterioration of cognitive functioning, and brain plaques and neurofibrillary tangles at autopsy (Barclay, 1986). Although much research has been done since this initial finding, the exact cause of the disease remains unknown (Terry, 1985). This insidious disease is considered to be the most common cause of severe intellectual impairment in persons over the age of 65 and affects 4-6% of that age group (Rosen, 1984). Almost 12% of the population of the United States is age 65 years or older, representing over 27 million persons. By the year 2030 it is estimated that 56 million persons will be over age 65, about 20% of the population (Maletta, 1984). In addition, there has been a significant decrease in the number of deaths for persons 85 and older (Powers & Dougherty, 1985). These figures would mean that between 2,240,000-3,360,000 persons could be affected by Alzheimer's Disease within 43 years.

Alzheimer's Disease, also known as Presenile Adult Dementia (PSAD) or Senile Dementia Alzheimer Type (SDAT), is

an irreversible and progressive brain disease that produces severe intellectual impairment and eventually leads to death. It is characterized by severe atrophy of the brain cortex and ventricular enlargement, senile plaques and neurofibrillary tangles, and degenerating nerve cells (Gwyther & Matteson, 1983). This disease is credited with being the fourth and fifth leading cause of death in the United States (Rosen, 1984).

The affected individual experiences Alzheimer's Disease in three stages. The first stage is characterized by vague symptoms such as headaches, insomnia, irritability, emotional lability, spatial disorientation, and memory lapses (Cybyk, 1980). The second stage may last for years and is characterized by progressive memory loss, aphasia, agnosia, and apraxia. Most victims experience wandering and practice repetitive movements such as tapping, lip-licking, chewing, and folding movements. During this stage the diagnosis of Alzheimer's Disease is usually made. The third stage, known as the terminal stage, is usually short, lasting generally not more than one year. The affected individual becomes emaciated, uncommunicative, incontinent, and may develop grand mal seizures (Gwyther & Matteson, 1983).

Care for these individuals is based on the stage of the disease and the severity of the symptoms. Because of the vagueness of the symptoms in Stage I, often the affected

individual has no need for direct assistance in performing his/her activities of daily living. The need for assistance in Stage II becomes more noticeable. Much of this care focuses on protection of the individual and assistance in some aspects of daily living, such as grooming and preparing meals (Gwyther & Matteson, 1983). Stage III care is characterized by the dependence of the victim on a caregiver for virtually all aspects of care (Cybyk, 1980).

This researcher initially became interested in Alzheimer's Disease after her grandmother-in-law was diagnosed as having Alzheimer's Disease and subsequently moved into her daughter's home. The impact of this disease on both women has been alarming. The decrease in cognitive functioning of the mother was accompanied by an increase in frustration, depression, and guilt in the caregiver daughter. The researcher, a staff nurse on a nursing home care unit, also has watched the decline of several residents diagnosed with this disease and the impact it has had on the caregiver spouses.

Family members provide approximately 90% of the care for older, impaired persons. Institutionalizing the Alzheimer victim seems to be the last, rather than the first, resort of families (Hayter, 1982). Caregiving for these victims is a "labor-intensive vocation with no formal job description" (Maletta & Hepburn, 1986). The most common caretaker is a spouse who is under a tremendous amount of

stress to meet the demand of providing physical care on a 24-hour basis for the spouse. Fengler and Goodrich (1979) labeled the spouses of elderly men as the "hidden patients" because of the problems associated with such intense caregiving. Caregivers have stated that their major coping stresses are their own fatigue and lack of time for themselves and their other role responsibilities (Mace & Rabins, 1981).

Stress as a concept is difficult to define, but affects all individuals. Selye (1976) refers to stress as the nonspecific response of the body to any stressor on the body at a given time. Therefore, stress can be seen as arising out of the mismatch between demands made and ability to cope (Clarke, 1984). Stress must be seen as an individualized and personal appraisal by the affected individual. The factors that initiate stress are as varied as the mechanisms utilized to cope with these factors (Manfredi & Pickett, 1981). Coping is reacting to one or more stressors so as to maintain equilibrium and can occur through changes in the perception of the demand, a strengthening of the ability to cope, and an actual reduction in demand (Clarke, 1984). Stress causes physiologic and psychological symptoms, and chronic stress can cause depletion of an individual's natural resistance to environmental stressors (Rahe, 1979, cited in Vincent, 1985).

There are many factors that influence balance between perceived demand and coping ability. These factors include the caregiver's (a) emotional state, (b) interpersonal support systems, (c) coping behaviors and styles, (d) perception of control over the situation, and (e) ambiguity of the outcome of the situation. There are two types of coping: direct and indirect. Direct coping involves the individual in some action that will affect the stressor in some way. Indirect coping includes mechanisms which do not alter the stressor in actuality, but do alter the way the individual experiences or reacts to the stressor (Clarke, 1984). Various coping mechanisms have been identified as adaptive or maladaptive (Ziemer, 1982). Examples of adaptive behaviors include talking to others, exercising, and putting the problem in perspective. Maladaptive behaviors have been identified as crying, overeating, drinking, smoking, and/or substance abuse. Thus, when the coping is maladaptive, the caregiver's mental and physical health may be in jeopardy.

Many relatives of victims with Alzheimer's Disease have formed support groups as a way to balance perceived demand and coping ability. Regular attendance at Alzheimer support groups assists them to significantly decrease feelings of burden and reduce their depression (Mace & Rabins, 1981). Such support groups enhance the adaptive behaviors of talking to others and putting the problem in perspective.

A selected review of the literature reveals that several researchers have studied the caregivers of Alzheimer's victims. Zarit, Reever, and Bach-Peterson (1980) conducted a study examining the feelings of burden and stress of caregivers and the importance of support for caregivers. Zarit et al. found that enhancing the information support network of the older demented person also may prevent overwhelming the primary caregiver with the burden of care, which often leads to a breakdown of the family system. Later studies have been concerned with the problems and stresses encountered by professional caregivers and caregiver relatives of the victim (Chenoweth & Spencer, 1986; George & Gwyther, 1986; Hayter, 1982; Scott, Roberts, & Hutton, 1986). The few studies that have dealt with the spouses of Alzheimer's victims have not differentiated between the coping mechanisms of husbands and wives who are the primary caregivers of their Alzheimer spouses (Fitting, Rabins, Lucas, & Eastham, 1986; Zarit, Todd, & Zarit, 1986).

Research into the area of the coping mechanisms of male and female spousal caregivers can guide the Gerontological Nurse Clinician (GNC) in developing individualized plans of support for the caregiver. The GNC is in a unique position to assist these caregivers with some of the dilemmas facing them in the day-to-day care of their spouses. The clinician can help the caregiver to recognize individual stressors and coping mechanisms and distinguish between adaptive and

maladaptive ones. If in fact a difference is found in the way male and female spouses cope with stress, the GNC can identify specific mechanisms which would be beneficial to that particular spouse.

The purpose of this research was to identify the differences in coping strategies of male and female spouses of Alzheimer patients. The question this researcher sought to answer was: How do the coping strategies of wives of Alzheimer victims differ from the coping strategies of husbands of Alzheimer victims?

Chapter II

Theoretical Basis of Study

Roy's theory of nursing is used as the theoretical framework for this research study about the differences in the coping strategies of spousal caregivers of Alzheimer victims. Roy's model is viewed primarily as a systems model but also contains interactionist levels of analysis. The person is defined as a "living, complex, adaptive system with internal processes (the cognator and regulator) acting to maintain adaptation in the four adaptive modes: physiological needs, self-concept, role function, and interdependence" (Marriner, 1986, p. 299). The person is recognized as a "biopsychosocial being in constant interaction with a changing environment" (p. 180) and is a whole made up of several parts which function as a unity for some express purpose (Roy, 1976).

The Adaptation Model of Nursing contains several basic assumptions that further explain the mechanism of coping. In order to cope with a changing world, the individual uses either natural (innate) or learned (acquired) reactions. Adaptation must occur if the individual is to respond positively to environmental changes and is determined by the combined effect of three classes of stimuli: (a) focal

stimuli, or stimuli immediately confronting the individual, (b) contextual stimuli, or all other stimuli present, and (c) residual stimuli, such as beliefs, attitudes, or traits (Riehl & Roy, 1980).

The individual, as an adaptive system, must deal with stimuli from the internal and external environment. These stimuli activate the coping mechanisms which in turn produce behavioral responses that may be either adaptive or maladaptive. The adaptive process promotes the integrity or wholeness of the person in terms of the goals of survival, growth, reproduction, and mastery. The maladaptive process is ineffective and does not contribute to the goals or integrity of the person. When coping mechanisms are ineffective, illness results. Health resumes when the client effectively adapts.

According to Roy, the goal of nursing is to help the individual adapt to the changes in his/her physiological needs, self-concept, role function, and interdependence relations during health and illness. The nursing process is used to facilitate the adaptation of the person. The Gerontological Nurse Clinician (GNC) can fill a unique role as a facilitator of adaptation by assessing behavior in each of those four adaptive modes, and intervening by assisting in the recognition and the management of the influencing stimuli by the client. The nursing process--assessment, diagnosis, goal setting, intervention, and evaluation--is

seen as the way to facilitate the adaptation of the client (Marriner, 1986).

In this study, the elderly spousal caregiver is the system of interest. Stimuli to which he/she must respond are both internal and external. External stimuli include the demands of caring for a debilitated spouse and his/her own physical limitations. Internal stimuli include his/her own views of self-worth, duty, and past reactions to stressors. Each person has his/her own ingrained thoughts which have resulted from past experiences. These stimuli activate coping processes which include crying, alcohol use, and withdrawal, and can be viewed as either adaptive or maladaptive processes. The coping responses, such as crying or talking with someone, promote the integrity of the person and survival, and are classified as adaptive. The coping responses such as alcohol or drug use and hiding feelings do not promote the integrity of the person and are classified as maladaptive. By identifying the most frequently used coping response, the GNC can assist the caregiver to use adaptive coping processes and promote wellness in the caregiver.

Chapter III

Hypothesis

Theoretical Null Hypothesis

When the coping strategies of husbands and wives who care for spouses with Alzheimer's Disease are compared, there will be no difference.

Theoretical Definitions

1. Coping strategies: as measured by the Chronicity Impact and Coping Instrument: Spouse Questionnaire.

2. Husbands: males between the ages of 45-95 who are married to, and provide the primary care for, a woman living at home with Alzheimer's Disease.

3. Wives: females between the ages of 45-95 who are married to, and provide primary care for, a man living at home with Alzheimer's Disease.

4. Alzheimer's Disease: progressive degenerative neurological condition.

5. Compared: utilizing percentiles.

Operational Hypothesis

When the coping strategies, as measured by the Chronicity Impact and Coping Instrument: Spouse Questionnaire, of husbands and wives between the ages of 45-95 who

provide the primary care for spouses with Alzheimer's Disease living at home, are compared utilizing percentiles, there will be no difference.

Chapter IV

Review of the Literature

The review of literature indicated that stress is an integral part of a caregiver's day. There is limited research concerned with the difference in coping strategies of male and female caregivers of Alzheimer spouses. Therefore, the review of literature discussed studies of family members as caregivers, spousal caregivers, and coping mechanisms.

Family Members as Caregivers

Zarit, Reever, and Bach-Peterson (1980) investigated the possible factors contributing to the feelings of burden of caregivers of older persons with senile dementia. In the study, 29 elders with senile dementia and their 29 primary caregivers were interviewed. The elder group consisted of 16 white males and 13 white females, with a mean age of 76 years. The age range of the caregivers was 68 to 82. Twenty-five of the caregivers were female and 4 male. Eighteen caregivers were spouses and 11 were daughters. The elderly demented victims were noninstitutionalized.

The demented individual and his/her caregiver were interviewed in the individual's home. The interview lasted

approximately 1 1/2 hours, and questionnaires were utilized. The demented individual's cognitive impairment was determined by the scores on the Mental Status Quotient (MSQ), the Face-Hand Test (FHT), and a 30-item mental status test developed by Jacobs, Bernhardt, and Strain (cited in Zarit et al., 1980). The demented individual's physical limitations were determined using Lawton's (1971) Physical and Instrumental Activity of Daily Living Scales (PIADL) (cited in Zarit et al., 1980). Instruments administered to caregivers included the Memory and Behavior Problems Checklist, a short version of the PIADL and a 29-item self-report inventory.

Results indicated that the extent of burden reported by the primary caregivers of persons with senile dementia was associated with the social supports available rather than to the behavioral problems caused by the illness. The authors suggested that the rate of institutionalization of the elderly dementia victims could be decreased if the formal support network of the dementia victim could be enhanced. This study became a pivotal one for further research of caregiver stresses.

George and Gwyther (1986) examined the well-being of family caregivers of elderly memory-impaired adults. In this study, 510 family caregivers of older persons suffering from Alzheimer's Disease or a related disorder, responded to a mail-out questionnaire. Caregivers were on the mailing

list of the Duke University Family Support Program. The majority of the caregivers in the sample lived with the individual for whom they provided care but some only assisted with care. The sample was 71% female and 29% male. The age range was 21 to 90 years with a mean age of 57. Most caregivers were the spouses or adult children of the patients. Eighty-eight percent of the respondents were married, with equal and small proportions of divorced, widowed, and never married caregivers. Ninety-seven percent were white, 2% black, and 1% were American Indian and Asian. The mean level of education for the caregivers was 12th grade. The survey consisted of several parts: physical health measurements, mental health measurements, psychotrophic medication usage, financial resources, social resources, and patient illness characteristics.

The results suggested that the caregivers experienced more stress, took more prescribed psychotropic drugs, participated in fewer social and recreational activities, and were less satisfied with the quality of their leisure activities than the general population. Females exhibited lower levels of well-being than males, and the feeling that one has the support of friends and family was more important for caregiver well-being than the actual amount of assistance received.

Chenoweth and Spencer (1986) studied the experiences and problems encountered by the family member caregivers of

persons with Alzheimer's Disease. For this study a 24-page questionnaire which consisted of open-ended questions, yes/no questions, and checklists was mailed out to a random sample of 413 families on the mailing list of the Minnesota Chapter of the Alzheimer's Disease and Related Disorders Association (ADRDA). Two hundred eighty-nine people responded, and 130 were caring for their relatives at home. One hundred fifty-nine had relatives in nursing homes or other institutions. The majority of the respondents were the primary caregivers for their relatives with dementia. Over half were spouses, and half were between 50 and 70 years of age. Several of the caregivers were in their 20s, and the oldest was 85. The family experiences reported by the caregivers were varied, but supportive of the findings of other caregiver studies. The researchers concluded that most families of dementia patients experience a momentous amount of emotional stress throughout their relative's illness, but that the amount and type of stress depends upon the phase of the illness.

Spousal Caregivers

Zarit, Todd, and Zarit (1986) investigated the changes that occur over time for the spousal caregivers of demential patients. In this study, a 2-year follow-up was conducted using a sample of male and female spousal caregivers of a spouse with senile dementia. The original sample for study by Zarit et al. (1980) was comprised of 33 wives and 31

husbands who were the caregivers for their demented spouses who lived at home. Each dementia victim was administered the Mental Status Questionnaire (MSQ) and the Face-Hand Test (Kahn, Goldfarb, Pollock, & Peck, cited in Zarit et al., 1980) to determine cognitive impairment. Each caregiver was administered a 20-item Burden Interview (Zarit et al., 1980) to measure perceived burden. The caregivers were asked to indicate how often each listed problem occurred with a range from 0 (never occurred) to 4 (occurs daily or more often). The subjects were also asked to rate how well they were able to tolerate the problem, with the ranges from 0 (I can tolerate this behavior when it occurs) to 4 (I can no longer tolerate this behavior and have to do something about it). The frequency of the occurrences multiplied by the tolerance of the behavior resulted in a cross-product score that was used in the comparison. Caregiver husbands reported less burden than caregiver wives. This finding appeared to be related to the husbands' greater tolerance of memory and behavior problems. For caregiver wives, the quality of the past relationship and the cross-product score for the Memory and Behavior Problem Checklist were significantly associated with burden. For the caregiver husbands, only the cross-product score was found to be a significant factor.

For the follow-up study, the caregivers were contacted after approximately 2 years and asked about the current status of the patient. The sample was comprised of 58

participants. Of the original caregivers, 17 husbands and 15 wives still cared for their spouses at home, 6 husbands and 5 wives placed their spouses in nursing homes, 4 husbands and 11 wives had spouses who were deceased, and one caregiver husband was deceased. Data for 2 caregiver husbands and 3 caregiver wives were unavailable. Excluded in this study were the caregivers whose spouses were deceased. The caregivers were administered the Burden Interview, and the dementia victims were readministered the MSQ and Face-Hand Test. Because of the limited time, no attempt was made to retest the patients who were placed in nursing homes. The caregivers who had placed their spouses in nursing homes were also given a series of questions inquiring about factors affecting their decision for placement.

There were lower cross-product scores of these caregivers on this follow-up study. Longitudinal analysis suggests that the spousal caregiver's ability to tolerate problem behaviors increases, even as the dementing disease progresses. Some of the most troublesome behaviors of the demented spouses either diminished in frequency or ceased, while an increased number of deficits in daily living became more prominent. The difference in perceived burden between husbands and wives at the time of the first study was no longer apparent in the 20-year follow-up. The investigators

felt that many of the wives had adopted a coping style similar to that of the husbands (Zarit et al., 1986).

Fittig, Rabins, Lucas, and Eastham (1986) compared the perceptions of the caregiving role by the spouses of dementia victims. The sample consisted of 28 caregiver husbands and 26 caregiver wives. The caregivers ranged in age from 50 to 90 years. The median age was 67 years. The Family Environment Scale (FES), Burden Interview, and Minnesota Multiphasic Personality Inventory (MMPI) were administered to each caregiver. Included were an additional nine questions designed by Goldberg (1982) to measure the extent and strength of social networks, four questions to determine the changes in the marital relationship and caregiving experience, and questions to gather demographic data.

The spousal caregivers experienced similar degrees of burden with more depressive symptoms reported by the wives. The younger group (50-66) had higher elevations on MMPI scales 4 (Psychopathic Deviate) and 6 (Paranoia) than the older group (67-90). The study confirmed the previous work of Zarit et al. (1980) that no relationship was found between the severity of dementia and the caregiver's perception of burden. Twenty-five percent of the caregiver husbands reported an improved relationship with their spouse since they assumed the caregiver role. The researchers concluded that caregiving husbands and wives experience the caregiving role in similar ways. Younger wives and older

husbands are more burdened and need more care from clinicians working with the dementia victims' families than their counterparts.

Coping Mechanisms

Pearlin and Schooler (1978) studied the different coping mechanisms employed by persons experiencing varied daily living stressors, and compared the findings based on sex, age, education, and income. A cluster sample of households was drawn and 2,300 people representative of the population of Chicago were interviewed. The ages ranged from 18 to 65 years. The interview process consisted of three distinct areas of questioning. The first area was concerned with potential life strains such as conflicts, frustrations, and threats. The second section consisted of questions about the coping repertoires people employ in dealing with the strains they experienced. The third area of questioning inquired into the emotional stresses that people feel and the extent to which they experience symptoms associated with depression and anxiety. This study suggested that the style and content of coping makes a difference in the emotional well-being of people, and the greater the score's variety of the individual's coping repertoire, the more protection is afforded him/her. Also suggested was the idea that society places more life strain on the individuals least equipped to cope effectively. The authors recommended possible intervention by persons capable

of identifying adaptive versus maladaptive coping strategies for these individuals at risk because of inadequate coping mechanisms.

Summary

Stress as an integral part of a caregiver's day has been documented by various research studies, and the coping mechanisms utilized to deal with this stress have been shown to be either adaptive or maladaptive. Most studies have examined the coping mechanisms utilized by the caregiver without differentiating their relationship to the affected individual. Since very few studies have specifically examined the different coping mechanisms utilized by male and female spousal caregivers, there is a need for further research.

Chapter V

Research Design and Methodology

Research Design

The research design used in this study is descriptive. According to Polit and Hungler (1983), descriptive research has as its main objective the "accurate portrayal of the characteristics of persons, situations, or groups, and the frequency with which certain phenomena occur" (p. 613). Since this study involves the comparison of percentile differences to examine the coping strategies of husbands and wives of Alzheimer victims, this method is appropriate.

Variables

The variable of interest is the coping methods of spouses of Alzheimer victims as measured by the Chronicity Impact and Coping Instrument: Spouse Questionnaire (see Appendix A). The controlled variable is membership in an Alzheimer support group. The intervening variables include honesty in answering questions, previous coping strategies, health and mental state at the time the questionnaire was answered, and the stage of the disease of the spouse.

Setting, Population, and Sample

The setting for this research study is an urban Central Mississippi city located in a county with a population of 258,000. All socioeconomic classes and educational backgrounds are represented in this setting. The racial breakdown is 116,358 (45.1%) Black, 140,094 (54.3%) Caucasian, and 1,548 (0.6%) Other. There are 58,824 (22.8%) persons age 50 or more years. The median income for this county is approximately $23,000 (Jackson Chamber of Commerce, 1986). There is an active Council on Aging and Human Resources in the city which sends representatives to the support group meetings. There are approximately 200 members of the only Alzheimer support group in this area. The meetings are held once a month, with an average number of 30 attendees. Most of the attendees are the children of Alzheimer victims, or health-care professionals with an interest in the disease. There are only three spousal caregivers who attend on a regular basis. The group has not yet affiliated with the national support group because of the lack of funds, but feasibility studies are continuing.

The population for this study is the spouses of those persons with Alzheimer's who are members of the local Alzheimer support group. The sample includes all members of the Alzheimer support group who had a spouse with Alzheimer's at home, cared for the Alzheimer spouse at home, and was the primary caregiver of the Alzheimer spouse. The

projected sample size was 50. The actual sample size was 14.

Data-Gathering Process

The researcher contacted the director of the local Alzheimer support group in person and explained the purpose and methodology of the study and obtained approval to use the support group's mailing list. This researcher did not have access to the names or addresses of the members due to confidentiality. The members' names and addresses were placed on the sealed envelopes by the researcher in the presence of the director and mailed. The envelopes contained a subject information form (see Appendix B); questionnaire; and a stamped, self-addressed envelope to be used by the participant in returning the questionnaire. The time frame for data collection was June-July, 1987.

Instrumentation

The Chronicity Impact and Coping Instrument: Spouse Questionnaire was modified by this researcher from the Chronicity Impact and Coping Instrument: Parent Questionnaire (CICI:PQ) developed by Hymovich (1981). The CICI:PQ was developed to measure the impact of caring for a child with a chronic disease and the coping mechanisms used by the caregiving parents. The tool was adapted by this researcher to measure the impact of Alzheimer's Disease on spousal caregivers. Questions that pertained specifically to

problems with children were eliminated, and the wording was changed to be specific to Alzheimer's Disease. The modified tool consisted of 40 questions--divided into five sections. Section A consisted of nine questions which dealt with the spouse and caregiver's questions about the disease and management of care. Section B consisted of nine questions which related to the caregiver and his/her reactions to stress. Contained within this section was a block of 13 questions which asked about coping strategies utilized by the caregiving spouse. The respondent chose how he/she reacted to everyday stressors and the benefit accrued from each mechanism. Section C consisted of two questions which dealt with the children in the family. Section D consisted of four questions about any hospitalizations of the spouse since the diagnosis of Alzheimer's Disease. Section E consisted of 16 questions about the caregiver and demographics. Scoring of the responses to Section B, Part 3, was by percentiles. This adapted tool was reviewed by a panel of experts and pretested with two spouses of Alzheimer victims not included in the study. Reliability had not been established.

Statistical Analysis

This researcher analyzed data from Section B, Part 3, by the use of percentiles.

Assumptions

1. The participants will answer truthfully the questionnaire.

2. Coping strategies can be measured.

Limitations

1. Limitation of the study to one geographic area prevents generalization to other areas.

2. Limitation of the study to members of a support group prevents generalization to caregiver spouses who are not members of a support group.

3. Limitation of the study to spousal caregivers prevents generalization to other caregivers of Alzheimer's Disease victims.

Chapter VI

Analysis of Data

The purpose of this study was to identify the difference in coping strategies of male and female spouses of Alzheimer victims. Data were collected from the members of an Alzheimer support group utilizing the Chronicity Impact and Coping Instrument: Spouse Questionnaire as a mail-out questionnaire. A total of 14 subjects met the criteria for the study. Subjects ranged in age from 60-96 years with an average age of 68.9 years. One Black and 13 Caucasians participated. The ages of the spouses with Alzheimer's Disease ranged from 59 to 90 years, with an average age of 72 years. The average number of years elapsed since the diagnosis of Alzheimer's had been made was 4.28. The length of time married ranged from 10 to 63 years, with an average of 44.38 years. The number of children of these subjects ranged from 0 to 5, with an average of 2.78.

Three males participated in the study. Two were age 78 and one age 63. All three were Caucasian. Their spouses were 80, 78, and 60 years old. They had been married 59, 57, and 35 years, respectively. One subject's spouse had been diagnosed as having Alzheimer's Disease for 3 years, one 4 years, and one 1 year. All 3 caregivers attended the

monthly support groups frequently and had someone to care for their spouses for one day or a week or longer in case of emergency.

Eleven females participated in the study. Their ages ranged from 60 to 85 years with an average age of 67.8 years. One caregiver was Black and 10 were Caucasian. They had been married an average of 42.6 years, with a range of 10-63 years. The length of time since the spouse had been diagnosed with Alzheimer's Disease ranged from 2 to 9 years with an average of 4.28 years. Three female caregivers never attended the meetings, two attended occasionally, one attended frequently, and one did not answer. These subject data can be found in Table 1.

Hypothesis

This researcher hypothesized that when the coping strategies, as measured by the Chronicity Impact and Coping Instrument: Spouse Questionnaire, of husbands and wives between the ages of 45 to 95 years who care for spouses with Alzheimer's Disease are compared utilizing percentiles, there would be no difference.

For the purpose of discussion, each type of coping mechanism will be addressed individually. For the coping mechanism "Crying," 0 (0%) of the males and 7 (64%) of the females checked "Do more." For the coping mechanism "Busy self with other things," 1 (33.3%) of the males and 7 (64%) of the females chose "Do more." For the coping mechanism

Table 1

Subject Demographic Data

Subject	Age	Race[a]	Sex[b]	Age of spouse	Length of time married	Number of children	Length of time of diagnosis (# of yrs)	Severity of condition[c]	Other to care for spouse 1 day	Other to care for spouse ≥ 1 wk	Attendance at Support Group[d]
S_1	86	C	F	90	63	1	2	MS	Yes	Yes	-
S_2	69	C	F	74	48	3	9	V	No	Yes	Nv
S_3	71	B	F	74	-	5	2	MS	No	No	R
S_4	78	C	M	80	59	3	3	MS	Yes	Yes	Fr
S_5	78	C	M	78	57	4	4	MS	Yes	Yes	Fr
S_6	68	C	F	70	50	3	5	MS	Yes	No	R
S_7	65	C	F	68	40	2	3	V	Yes	Yes	F
S_8	61	C	F	59	40	4	4	MS	Yes	No	O
S_9	62	C	F	63	10	0	6	V	No	No	Nv
S_{10}	67	C	F	70	43	3	4	MS	No	No	Nv
S_{11}	60	C	F	68	42	3	5	V	Yes	Yes	R
S_{12}	67	C	F	69	49	4	4	MS	Yes	No	O
S_{13}	63	C	M	60	35	2	1	S	Yes	Yes	Fr
S_{14}	70	C	F	81	41	2	3	MS	No	No	R

[a]B = Black. C = Caucasian. [b]F = Female. M = Male. [c]MS = Moderately severe. V = Very severe. S = Slightly severe.

[d]Nv = Never. R = Rarely. Fr = Frequently. O = Occasionally. - = Did not answer.

"Exercise," 0 (0%) of the males and 4 (36%) of the females checked "Do more." These three mechanisms were chosen more often by the females than the males. The males chose "Ignore/try to forget," "Hide feelings," "Smoke," "Yell/scream/slam doors," and "Ask for help" more often than females. For "Ignore/try to forget," 2 (66.7%) of the males and 3 (27%) of the females chose "Do more." Three (100%) of the males and 6 (55%) of the females chose "Do more" for "Hide feelings." There was equal distribution for "Smoke" and "Yes/scream/slam doors" of 1 (33.3%) of the males and 1 (9%) of the women choosing "Do more." Males tended to "Ask for help" more often 2 (66.7%) than females 4, (36%). For the coping mechanism "Get away," 3 (100%) of the males and 7 (64%) of the females chose "Do less," and 1 (33.3%) of the males and 1 (9%) of the females "Asked for help" less often. Females used a greater variety of coping mechanisms while males used 8 of 13. Since differences in coping strategies of female and male caregivers were identified, the researcher rejected the null hypothesis. These data along with the other comparisons are presented in Table 2.

Additional Findings

This researcher collected certain data not directly related to the hypothesis, but considered to be of interest for further studies. Several individuals who received the questionnaire called this researcher at home to express their desire to see a similar questionnaire for other

Table 2

Analyzation by Percentiles of Coping Mechanisms Utilized by Males and Females

	Do less				Do about the same				Do more			
	Male		Female		Male		Female		Male		Female	
Coping Strategy	f	%	f	%	f	%	f	%	f	%	f	%
Cry	0	0.0	0	0	3	100.0	4	36	0	0.0	7	64
Busy self with other things	0	0.0	0	0	2	66.7	4	36	1	33.3	7	64
Talk with someone	0	0.0	2	18	2	66.7	5	45	1	33.3	4	36
Ignore/try to forget	1	33.3	4	36	0	0.0	4	36	2	66.7	3	27
Hide feelings	0	0.0	0	0	0	0.0	5	45	3	100.0	6	55
Get away	3	100.0	7	64	0	0.0	4	36	0	0.0	0	0
Smoke	0	0.0	1	9	2	66.7	9	82	1	33.3	1	9
Yell/scream/slam doors	0	0.0	1	9	2	66.7	9	82	1	33.3	1	9
Exercise	1	33.3	2	18	2	66.7	5	45	0	0.0	4	36
Ask for help	1	33.3	1	9	0	0.0	6	55	2	66.7	4	36
Take alcohol/drugs	0	0.0	1	9	3	100.0	10	91	0	0.0	0	0
Pray	0	0.0	0	0	0	0.0	3	27	2	66.7	8	73
Take medicine	0	0.0	0	0	3	100.0	8	73	0	0.0	3	27

caregivers. One man called to talk about his wife who had died 2 years ago, and said that the questionnaire brought back a great deal of pain, but wanted to complete it and mail any way for additional information. This researcher received five questionnaires completed by the children of Alzheimer victims. They indicated that they were aware that they did not meet the study criteria, but wanted their responses noted. This was a completely unexpected occurrence, since the questionnaire was 10 pages in length and required a great deal of thought on the part of the respondent.

Chapter VII

Summary, Conclusions, Implications, and Recommendations

Summary

This study was descriptive in nature, designed to identify differences in coping strategies of spouses of Alzheimer patients who are cared for at home. Data were collected using the Chronicity Impact and Coping Instrument: Spouse Questionnaire.

The sample consisted of 14 subjects (3 males and 11 females) who met the criteria for the study. Subjects ranged in age from 60 to 86 years with an average age of 68.9 years. One Black and 13 Caucasians participated.

To test the hypothesis, data were analyzed using percentiles. Eight coping strategies were found to be used "More often" by the participants. Males chose "Ignore/try to forget," "Hide feelings," "Smoke," and "Yell/scream/slam doors," and "Ask for help" more often than females. The females chose "Cry," "Busy self with other things," and "Exercise" more often than males. The males chose to "Get away" and "Ask for help" less often than the females. None of the participants chose "Get away more" as a coping strategy. Females chose a variety of coping strategies.

Since differences in coping strategies were identified, the researcher rejected the null hypothesis.

Conclusions and Implications

This study found a difference between the coping strategies utilized by male and female spousal caregivers of Alzheimer victims. Males "Got away" and "Asked for help" much less often than females. This supports previous research which found that caregivers participated in fewer social activities (George & Gwyther, 1986). In this study, 3 (100%) of the males and 7 (64%) of the females "Got away" less and none of them "Got away" more. The Gerontological Nurse Clinician (GNC) can assist the caregiver in exploring options to enable him/her to get out of the home more often.

This study does not support research that indicates that females exhibit lower levels of well-being than males (George & Gwyther, 1986). Pearlin and Schooler (1978) suggested that the greater the scope and variety of the individual's coping repertoire, the more emotionally protected he/she is. This researcher found that the females tended to use a greater variety of coping strategies than males. This finding needs to be considered in light of the small number of males in the sample. The GNC needs to assist males in developing a repertoire of coping strategies. This study needs to be replicated with a larger sample of men.

Findings of this study validate Roy's Adaptation Model of Nursing which states that adaptation to a changing environment must occur if the individual is to cope. This study also demonstrates that people cope in different ways to a variety of stressors. More research needs to be conducted to find out which strategies promote adaptation. In this study only the strategies for coping were explored. The researcher made no attempt to determine the level of adaptation. The interest expressed by the caregivers who did not meet the criteria for being in the sample indicates that more research needs to be done that looks at the primary caregiver without confining it to spouses.

Several problems were found with the implementation of this study. The length of the tool (10 pages) could have accounted for the low number of returns of the questionnaire. The section on coping strategies did not allow for statistical analysis. The time restrictions on data collection made it difficult to contact other support groups and obtain permission to collect data from their members.

Recommendations

The following recommendations are made based on the findings of this study:

Research

1. Replication of the study utilizing a larger sample size.

2. Conduction of a similar study utilizing a different tool which would allow for statistical analysis.

3. Replication of the study utilizing a randomized sample to ensure equal representation by race and sex.

4. Conduction of a similar study examining coping strategies of all caregivers of Alzheimer victims.

Nursing

1. Inclusion of an assessment of coping strategies of caregivers of Alzheimer patients.

2. Implementation of interventions to reduce stress or to change maladaptive coping strategies or caregivers as needed.

3. Provision of the opportunity for caregivers to discuss stressors associated with caregiving.

4. Encouragement of males to use a variety of coping strategies.

Appendix A

Date_____
Subject #_____

Chronicity Impact and Coping Instrument:

Spouse Questionnaire

Is your spouse cared for at home?

____ (1) No
____ (2) Yes

Who provides the primary care for your spouse?

____ (1) Self
____ (2) Child
____ (3) Other (please specify)

Section A: Your Spouse

1. How old is your spouse? _____

2. What was your spouse's occupation? (Please state what your spouse did--not place of employment)_____

_____

3. What grade in school did your spouse complete? _____

4. When was your spouse's Alzheimer's disease first diagnosed?

_____

5. How severe would you say your spouse's condition is presently?

____ (1) Not severe (slight)
____ (2) Moderately severe
____ (3) Very severe

6. Does anyone you know (family/friends) have the same illness as your spouse?

____ (1) No
____ (2) Yes

If yes, who?

____ (1) Brother(s) or sister(s)
____ (2) Spouse's brother(s) or sister(s)
____ (3) Parent
____ (4) Spouse's parent
____ (5) Grandparent
____ (6) Spouse's grandparent
____ (7) Friend

7. How has your spouse's physical health been during the past 3 months?

____ (1) Excellent
____ (2) Very good
____ (3) Good
____ (4) Fair
____ (5) Poor

8. Please indicate if you would or would not like to have help with or discuss any of the following:

	Would not like (2)	Does not apply (3)	Would like (1)
Physical care of spouse			
Diet/nutrition for spouse			
Sleep habits of spouse			
Recreational activities for spouse			
Managing spouse's behavior			
Medicines			
Dental needs of spouse			
Information about expected outcome of Alzheimer's disease			
Information about spouse's disease			
Other: What?			

9. What have you done in the past when you have needed information or help with any of the areas listed in Question 8? (Please check as many as apply)

____ (1) Have not needed any help.

____ (2) Wrote away to others.

____ (3) Asked the clergy.

____ (4) Went to the library.

____ (5) Asked doctor or nurse.

____ (6) Asked friends or relatives.

____ (7) Asked other spouses of Alzheimer's disease victims.

____ (8) Nothing.

____ (9) Talked to others. Who?_____

____ (10) Have not known what to do.

____ (11) Support groups.

____ (12) Other: What?_____

Section B: Yourself

1. How satisfied are you with your relationship with your spouse?

____ (1) Not sure

____ (2) Very satisfied

____ (3) Somewhat satisfied

____ (4) Somewhat dissatisfied

____ (5) Very dissatisfied

2. All spouses have some areas of concern. During the past 3 months, how much of a concern have the following areas been for you? (Please put an "X" in the appropriate column)

Concerns	None/Does not apply (1)	A little bit (2)	Quite a bit (3)	A great deal (4)
Extra demands on my time				
Feeling worn out				
Enough fun and relaxation as I would like				
Talking with or understanding my spouse				
Sexual relationship with my spouse				
Making my spouse comfortable or happy				
Enough time or attention from spouse				
Getting out of house together with spouse				
Getting out of house alone				
Whether I am taking care of spouse in the best way				
Having to travel too far for medical help				
The weather influencing what my spouse is able to do				
Having enough insurance/money to meet expenses of spouse's care				
Having adequate agencies in the community providing care related to my spouse's needs				
Wondering about what my spouse's failure is likely to be				
The responsibility for caring for my spouse worries me				
Wondering whether to place spouse in nursing home				

3. People handle their concerns in many different ways. There are times when you may have more problems and concerns because of your spouse's condition. In what ways do you do things differently when these problems come up? (Please put an "X" in the appropriate column.)

	Do less	Do about the same	Do more	Does this help? (Y)	(N)
Cry					
Busy self with other things					
Talk with someone					
Ignore/try to forget					
Hide feelings					
Get away					
Smoke					
Yell/scream/slam doors					
Exercise					
Ask for help					
Take alcohol/drugs					
Pray					
Take medicine					

4. Are you a member of an association related to your spouse's illness?

____ (1) No ____ (2) Yes

a. If yes, how often do you attend meetings?

____ (1) Frequently
____ (2) Occasionally
____ (3) Rarely
____ (4) Never

b. If you go to the meetings, how helpful have they been?

____ (1) Very helpful
____ (2) Somewhat helpful
____ (3) Not very helpful
____ (4) Not helpful at all

c. Where is the association located?_____

5. Do you have someone who could take care of your spouse for a day in case of an emergency (such as if you become ill and cannot take care of your spouse)?

____ (1) No ____ (2) Yes

If yes, what relationship:_____

6. Do you have someone who could take care of your spouse for a week or more in case of an emergency?

____ (1) No ____ (2) Not sure ____ (3) Yes

If yes, what relationship?_____

7. People have different beliefs about things that influence their lifestyle. Please indicate whether you agree with the beliefs stated below.

Beliefs	Agree (1)	Disagree (2)
People should take care of their own needs before they help their spouse.		
It is necessary to get out of the house often to relieve the strain of care.		
It is usually better not to show or talk about one's feelings to others.		
Sometimes just avoiding or trying to forget something makes it easier to handle.		
Sometimes getting away from a situation makes it easier to handle.		
I usually have control over things that happen to me or my family.		
It is lucky that this is the only condition my spouse has.		
My spouse's condition is always going to be there and there isn't much I can do about it.		
I sometimes think of my spouse's condition as a nuisance.		

8. How many times have you been married? _____

9. How many years have you been married? _____

Section C: Children

1. During the past 3 months, how much have you and your children talked about the following:

	Not at all (1)	A little bit (2)	A moderate amount (3)	A great deal (4)	Does not apply (5)
Information about the parent's disease					
How to take care of the ill parent					
Activities affected by Alzheimer's disease					
Providing assistance with the care of the ill parent					
Possibility of placing ill parent in a nursing home					

2. Please indicate whether you would like to have help in discussing any of the following with any of your children:

	Would not like (1)	Not sure (2)	Would like (3)
Information about expected progression of Alzheimer's disease			
Information about how to manage the behavior of the parent with Alzheimer's disease			
Physical needs			
Emotional needs			
Social needs			
Intellectual needs			

Section D: Hospitalization

1. Has your spouse been admitted to the hospital since the diagnosis?

   ____ (1) No (If no, go to Section E)

   ____ (2) Yes (If yes, continue)

2. How many times has your spouse been in the hospital since the diagnosis? _____

3. For how long were the majority of the hospital stays?

   _____

4. How satisfied were you with the care your spouse received during the last hospitalization?

   ____ (1) Very satisfied
   ____ (2) Somewhat satisfied
   ____ (3) Somewhat dissatisfied
   ____ (4) Very dissatisfied

5. Why was your spouse admitted to the hospital?

   _____

Section E: Other

1. How many children do you have? _____

2. How close do your children live to you? Check all that apply.

   ____ (1) Same house
   ____ (2) Same town
   ____ (3) 30 miles or less
   ____ (4) 60-100 miles
   ____ (5) More than 100 miles

3. How would you describe yourself?

   ____ (1) Caucasian
   ____ (2) Asian
   ____ (3) Black
   ____ (4) Spanish-American
   ____ (5) American Indian
   ____ (6) Indian
   ____ (7) Other: Specify _____

4. What is your religion?

____ (1) Catholic
____ (2) Jewish
____ (3) Protestant
____ (4) Other: What? _____
____ (5) No religion

5. How often have you attended religious services in the past 3 months?

____ (1) Frequently
____ (2) Occasionally
____ (3) Rarely
____ (4) Never

6. a. Are you employed now?

____ (1) No
____ (2) Yes

b. If yes, what type of work do you do?

_____

c. If yes, do you work:

____ (1) Full-time
____ (2) Part-time

7. Are you satisfied with your current employment status?

____ (1) No
____ (2) Not sure
____ (3) Yes

8. What is your age? _____

9. What grade in school have you completed? _____

10. How has your general health been during the past 3 months?

____ (1) Excellent
____ (2) Very good
____ (3) Good
____ (4) Fair
____ (5) Poor

11. What is your family's annual income?

____ (1) Under $5,000
____ (2) $ 5,000 - $10,000
____ (3) $11,000 - $20,000
____ (4) $21,000 - $30,000
____ (5) Over $30,000

12. Does anyone live in your home with you and your spouse?

____ (1) No
____ (2) Yes

If yes, identify relationship:

____ (1) Child
____ (2) Relative: Specify _____
____ (3) Friend
____ (4) Other: Specify _____

13. Do you have anything else to add that you would like me to know about yourself, your spouse, or other family members?

____ (1) No
____ (2) Yes

If yes, what? _____

Adapted from:

Hymovich, D. P. (1983). The Chronicity Impact and Coping Instrument: Parent Questionnaire (CICI:PQ). Nursing Research, 32(5),

Appendix B

Letter of Information

Title of Study:

The Differences in the Coping Strategies of

Male and Female Spouses of Alzheimer Victims

My name is Shelah Teeters, and I am a registered nurse and a graduate student at Mississippi University for Women. I am conducting a research survey involving the spouses of Alzheimer victims. It would be most helpful if you would agree to participate in my study by completing the enclosed questionnaire and sending it back to me in the enclosed self-addressed, stamped envelope. It is understood that return of this questionnaire will be considered informed consent. The information you give will be kept confidential, and no names will appear on the questionnaire.

I realize the demands on your time are great, but I believe that the results of this study will help to educate nurses about the specific needs of caregivers of Alzheimer victims. I will be glad to answer any questions you may have concerning the study if you will contact me at the number provided.

Gratefully,

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